

GRIEVING ACROSS THE
DEVELOPMENTAL SPECTRUM:
A REFERENCE GUIDE FOR PARENTS OF GRIEVING
CHILDREN AND ADOLESCENTS



CareFirst

The logo for CareFirst features a cluster of colorful dots in shades of red, orange, and yellow, arranged in a pattern that suggests a rising sun or a burst of energy. Below this graphic, the word "CareFirst" is written in a large, white, sans-serif font.



For Your Little One's Heart,

Has your little one recently lost someone they love? Is their heart hurting? It is never easy to lose someone who we have loved.

Maybe they spent a lot of time with them, or talked to them on the phone. Even though they cannot call or see that person anymore, they are still a part of them.

They may feel like no one could possibly understand what they are going through. They may feel like their heart could break into a million pieces. Although people grieve differently, everyone deals with death and the feeling of sadness that comes along with it.

At CareFirst, we want you to know that you are not alone. This book is designed to help parents and caregivers through this difficult time. Grief is a natural part of life. We hope that this reference guide can support you and your children as you begin healing your heart following your loss.

*Sincerely,
Your friends at CareFirst Grief Services*



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GRIEF IS *THE FEELINGS OF SADNESS, SORROW, DISTRESS, OR PAIN THAT PEOPLE HAVE SURROUNDING THE LOSS OF LOVED ONES, FRIENDS, AND EVEN PETS.*

Loss is an inevitable part of life, and grief is a natural part of the healing process. Grieving the loss of a loved one is difficult, especially for a teen or child. When a child experiences the loss of a loved one, it can have a profound impact on the rest of their life. Grief lasts as long as it takes to adjust to the changes in your life after a loss. It can last months, or even years. Grief has no time-frame; thoughts, emotions, behaviors, and other responses may come and go.

Situations that May Cause Grief:

Death of a friend or family member

Divorce

Loss of a pet

Cancellation of an event the child was looking forward to

Older sibling graduating or moving out of home

Moving to a new place

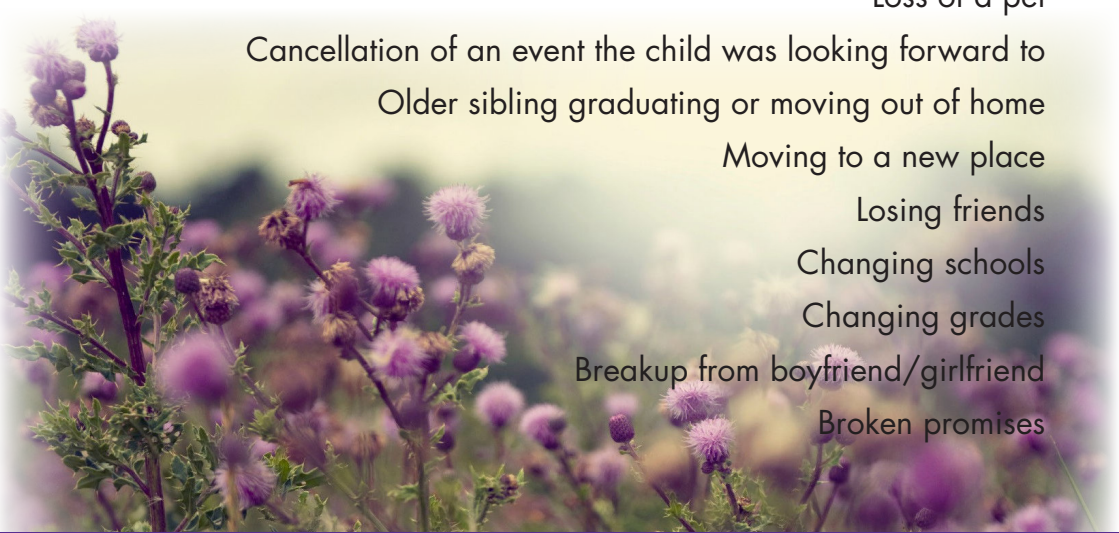
Losing friends

Changing schools

Changing grades

Breakup from boyfriend/girlfriend

Broken promises



The 5 Phases of Grief

The foundation of grief research was done by Elizabeth Kubler-Ross and is known as *the 5 Stages of Grief*...

- 1. Denial/Shock:** The initial thought process that “this can’t possibly be happening. Everything is OK and this is just a really bad dream.” This coping mechanism can last for a long time because it often feels better than reality.
- 2. Anger:** Once a person realizes that the loss is real, feelings of frustration and anger often result. Questions may include; “What did I do to deserve this?”; “How dare they leave me?”; “Why is this world unfair to just me?”.
- 3. Bargaining:** After working through the anger, people will often feel some hope once again. Children will start to wonder, “Maybe, if I’m really good, Dad will come back,” or “If I try to be perfect, maybe her cancer will go away”.
- 4. Grieving:** This is where someone feels all of the pain and hurt. This is the raw emotional place which is often accompanied by crying and depressed mood. Often the child feels hopeless.
- 5. Acceptance:** Eventually people will start to feel alright. Their periods of sadness decrease in duration and intensity as time goes on. Often, the memories that once brought sadness now bring good feelings and laughter.

(Kubler-Ross, 1969)

The Grief Spiral

More modern grief research discusses grief as a spiral where one moves through a series of feelings and emotions. One example of this is *The Grief Spiral*.

Another way grief is processed is through an ongoing series of cycles representing a spiral effect. This is known as *The Bowlby Model*, or *Grief Spiral*. These feelings are revolving, with some people experiencing some feelings multiple times.

Model: The Circle of Grief



(Bowlby, 1980)

Developmental Stages and Typical Responses

DEVELOPMENTAL STAGE	UNDERSTANDING OF DEATH	COMMON EMOTIONS & BEHAVIORS	HOW TO HELP
<p>Infants and Toddlers (ages 0 to 2 years old)</p>	<ul style="list-style-type: none"> • No understanding of death • 0-12 months: Unable to differentiate from temporary separation or abandonment • 12-24 months: Recognize death in terms of immobility, feel it is reversible or temporary • Separation from close loved one causes changes • React to change in routine • Read facial expressions and sense the emotions of people around them • Sense rather than understand that something has happened 	<ul style="list-style-type: none"> • Separation anxiety/fear of abandonment • Desire to be held • Regression of learned tasks and behaviors • Crying • Expressing feelings, thoughts, actions rather than words • Irritability and temper tantrums • Changes in sleep patterns • Changes in eating patterns • Decreased activity • Rocking and thrashing 	<ul style="list-style-type: none"> • Provide physical contact and reassurance (make time for play) • Attend to child's immediate physical needs • Maintain consistent routines • Include the child in the process of mourning when possible and appropriate • Be patient • Provide concrete rules and limits • Explain very simply and truthfully what has happened • Minimize separation from primary caregivers

(Southern Tier Hospice and Palliative Care, 2009)

Developmental Stages and Typical Responses

DEVELOPMENTAL STAGE	UNDERSTANDING OF DEATH	COMMON EMOTIONS & BEHAVIORS	HOW TO HELP
<p>Preschool (ages 2 to 5 years old)</p>	<ul style="list-style-type: none"> • Egocentric (believes world centers around them) • No cognitive understanding of permanence (believes that death is temporary and reversible) • Experience death as abandonment • Equate death to sleeping or being on a trip • "Magical thinking" may cause child to believe he/she caused the death or can bring the dead person back • May fantasize about events or situations being worse than reality 	<ul style="list-style-type: none"> • Crying • Fighting • Interest in dead things (e.g. bugs, animals) • Acting as if death never occurred • Regression of behaviors (issues with potty training or bed wetting) • Fear of sleeping alone • Asking repetitive questions • Intense, but brief grief reactions • Expressing strong feelings in his/her sleep and dreams • Expressing feelings through play • Worrying about safety and being abandoned - that others will die too 	<ul style="list-style-type: none"> • Give simple concrete explanations • Repeat answers as often as asked • Include child in family rituals and in the mourning process • Provide safe ways to express feelings (physical affection, nurturing) • Maintain structure and routine • Encourage play (read story books about death and loss) • Accept expressions of anger • Tolerate the child's need to regress for a while (ex. being held, sleeping with others, thumb sucking) • If grief is anticipatory, prepare the child for medical procedures and death

(Southern Tier Hospice and Palliative Care, 2009)

Developmental Stages and Typical Responses

DEVELOPMENTAL STAGE	UNDERSTANDING OF DEATH	COMMON EMOTIONS & BEHAVIORS	HOW TO HELP
<p>Elementary School (ages 5 to 9 years old)</p>	<ul style="list-style-type: none"> • Think about the finality of death and how frightening it is • Think about the biological processes of death • Think about death as a person or spirit (e.g. skeleton, monster, ghost) • Believe death is something that happens to others, not to them • Begin to realize that death is permanent, but still lack full comprehension • May worry about his/her own death and death of others • May feel guilt about the death • Associate death with bodily harm, mutilation, and disintegration 	<ul style="list-style-type: none"> • Regression • Fighting, anger • Trouble paying attention, daydreaming • Withdrawn • Sleepiness • Difficulty completing school assignments • Nightmares • Violent play • Attempt to take on role of person who died • Bed-wetting 	<ul style="list-style-type: none"> • Assist child with drawing and story writing • Provide objects and space for symbolic play • Talk about the death and feelings with the child • Provide demonstrations of physical expressions to go along with feeling words • Provide options for physical outlets to express energy and feelings • Maintain routines and structure, but be flexible • Provide socialization with peer group • Allow child to make some choices

(Southern Tier Hospice and Palliative Care, 2009)

Developmental Stages and Typical Responses

DEVELOPMENTAL STAGE	UNDERSTANDING OF DEATH	COMMON EMOTIONS & BEHAVIORS	HOW TO HELP
Middle School (ages 9 to 12 old)	<ul style="list-style-type: none"> • Operational thinking, along with logic • Understand as final and unavoidable • View death as punishment • See death as being personal and universal • Understand they will also die someday • Fascination with the details of death 	<ul style="list-style-type: none"> • Regression • Difficulties in school • Withdraw from friends • Acting out (role confusion) • Sleeping and eating disturbances • Overwhelming concern with deceased body • Suicidal thoughts (desire to join the deceased) • Strongly desire information • Often exhibit outward mourning 	<ul style="list-style-type: none"> • Answer questions as they are asked • Expect mood swings to be present and accept them when they occur • Offer choices about how to be involved in death and mourning rituals • Find or offer peer support groups • Encourage expression of feelings • Encourage activities such as reading, writing, art, music, and sports • Help label emotions • Talk about the situation

(Southern Tier Hospice and Palliative Care, 2009)

Developmental Stages and Typical Responses

DEVELOPMENTAL STAGE	UNDERSTANDING OF DEATH	COMMON EMOTIONS & BEHAVIORS	HOW TO HELP
High School (ages 12 years old and older)	<ul style="list-style-type: none"> • Formal operational thinking • Use abstract thinking • Understand the finality of death (can often sense their own impending death) • Believe that showing emotions is a sign of weakness; feel a need to be in control of feelings • Self-centered; will often have an exaggerated sense of their own role in regard to the death 	<ul style="list-style-type: none"> • Conflict about moving to independence and remaining dependent • Impulsive behavior or high risk behavior • Fighting, or arguing • Lack of concentration • Grieve for what might have been • Acts as though the death never happened • Change in grades • Change in sleeping or eating patterns • Change in peer groups 	<ul style="list-style-type: none"> • Be aware that often the thoughts and feelings of teens can be contradictory and inconsistent • Allow adolescent to make choices and participate in decision-making • Encourage self-care • Provide privacy when adolescent needs it (within safe limits) • Provide other people (friends, social workers) for adolescent to talk with • Keep in mind that the coping behavior of teens is often covering up their grief and it is okay as long as they are not harming themselves or others • Encourage them to share their feelings (encourage peer support groups)

(Southern Tier Hospice and Palliative Care, 2009)

Normal Grieving Responses in Children & Adolescents

Thought Patterns

- Disbelief
- Confusion
- Preoccupation
- Sense of the deceased's presence
- Hallucinations
- Desire to join the deceased

Physical Reactions

- Tightness in throat or chest
- Dry mouth
- Headache
- Stomach ache
- Eating problems
- Bed-wetting
- Tired/Run down
- Hypersensitivity to noise
- Lack of energy

Emotional Reactions

- Anger
- Anxiety
- Crying
- Guilt
- Loneliness
- Fatigue
- Overly sensitive

Behavioral Reactions

- Disruptive behavior
- Afraid to sleep alone
- Nightmares
- Temper tantrums
- Rocking
- Short, frequent outbursts
- Hard to follow directions
- Isolation from others
- Appetite disturbance

Supporting the Grief Journey

“Grief is not a disorder, a disease, or a sign of weakness. It is an emotional, physical, and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.”

~Earl Grollman



Supporting the Grief Journey

Grief is unique to each individual and there is no right or wrong way to grieve. The important thing is to be available to lend support when needed.

Children and teens often respond better to adults who offer companionship in the grief journey rather than direct it. Grief can be complex and confusing to everyone involved and it is important to identify your own struggles with grief in order to effectively help others process their grief.

Children and teens grieve differently than adults do. Peer relationships are particularly crucial to teens and often have a large impact on them when they experience loss. The death of a close friend may be more difficult to process than the death of a grandparent. This does not mean that these feelings of grief should be minimized, however. Teens are adults in the making, and to understand life, they must also understand death.



Response to Grief

As anyone grieves they may ask, "Is feeling this way natural?" *Though grief is natural, it doesn't feel natural because it is difficult to control the emotions, thoughts, and physical responses.* It can feel overwhelming to some and even frightening to feel like our emotions are out of control. Grief is ongoing and everyone grieves for different lengths of time.

As a result, a wide spectrum of emotions and sensations occur, causing different behaviors to surface in response to the death. It is not uncommon to cry after a death. It is not uncommon to use humor after a death. It is not uncommon to reject feelings of grief after a death. Grief doesn't follow a pattern or set of rules, and it cannot be evaluated or quantified. Every individual copes differently, and will have their own unique set of grief responses. Grief never ends, but changes character and intensity as an individual processes their loss.

The impact of a death on children and teens relates to a combination of factors:

- Social support system available (family, friends, community, etc.)
- Circumstances of the death - how, where, when
- Whether or not they found the body
- Nature of the relationship with the person who died (harmonious, abusive, fraught with conflict, etc.)
- Involvement in the dying process
- Emotional and developmental age
- Previous experience with death

Ways to Help

Pre-adolescents and teens will often test their own mortality following the death of someone they loved and have lost. Here are some ways to validate their feelings and reduce the chance of them engaging in risky behavior.

- Make time for grief
- Address their questions and validate his/her feelings
- Share your own feelings (do not be afraid to cry with them)
- Normalize reactions and feelings
- Be aware and sensitive to “grief bursts” and “trigger events”
- Maintain limits on behavior
- Be open to sharing facts appropriately. Be reasonable.
- Be direct; ask them what he/she wants to know
- Recognize when they need space to be alone
- Try to keep a routine or create a new consistent one to ensure structure
- Trust your own judgement

Keep in mind that coping behaviors are often there to cover up their grief and it is okay for them to use these coping techniques as long as they aren't a harm to themselves or others.

(Southern Tier Hospice and Palliative Care, 2009)

Comments From Grieving Kids

"No one at school understands anything."

"I feel very strange. Sometimes I feel like a totally different person since Dad died, and other times, I feel like nothing has happened."

"I hate it when people say, 'I'm sorry.'"

"Will I ever feel better?"

"I always feel like crying, but I hold it back, and then I just shut down."

"I'm jealous of friends who have a relationship with their parent."

"It's so quiet around my house now. I hate it."

"When Mom died, a part of me died too. I was being torn apart."

"I don't think I could ever walk into another hospital."

"I thought I was doing just fine after Grandpa died, but now I'm not too sure. I miss him more now than I did last year. I think about him all the time and I just want to talk to him again."

"I just don't belong anymore, anywhere, home or at school."

"The funeral seemed so stupid to me. All these people were saying things, but none of it helped. No amount of words will ever bring him back and no one can give me any good reason as to why he had to die. It's all unfair."

"Christmas last year without Sam was really sad. I don't know what to expect this Christmas."

"I feel as if Dad is still here. I can't believe he is really gone."

"People call the house and ask how my Mom is doing, not how I am doing."

"I hate the way my family has changed."

Grieving Teen's Bill of Rights

A grieving teen has the right to...

- Know the truth about the death, the deceased, and the circumstances
- Have questions answered honestly
- Be heard with dignity and respect
- Be silent and not talk about his/her grief emotions and thoughts
- Not agree with your perceptions and conclusions
- See the person who died and the place of death
- Grieve any way that she/he wants without hurting themselves or others
- Not have to follow the "Stages of Grief" as outlined in a high school health book
- Grieve in one's own unique, individual way without censorship
- Be angry at death, at the person who died, at God, at themselves, and at others
- Have his or her own theological and philosophical beliefs about life and death
- Be involved in the decisions about the rituals related to life and death
- Not be taken advantage of during this vulnerable mourning period
- Have guilt about how he or she could have done things differently

(The Dougy Center, 2017)

Common Experiences in Grief

Shock and Disbelief

This is the typical first reaction after learning of a loss. It is your body's way of temporarily protecting your mind from the impact of loss. During this phase, children and teens may:

- Have trouble believing their loved one is gone
- Feel numb and on "auto-pilot"
- Expect their loved one to appear
- Have a sense of being in a dream

Anger or Resentment

This is common even if there is no one to blame for the death. Kids may:

- Feel like the situation is unfair
- Feel angry at family and friends
- Feel angry at God
- Resent their loved one for dying

Guilt

It is normal to regret things you did or did not say and that you do or do not feel. children and teens may regret or feel guilty for:

- Not doing something (or not doing more) to prevent death
- Not being there to say goodbye
- Being relieved that the person died
- Having arguments with their loved one while he or she was alive

Fear and Anxiety

Loss brings many changes to everyday life and these changes can cause feelings of fear and anxiety. Kids may:

- Worry about taking on new or additional responsibilities
- Worry about "losing it"
- Fear their own impending death
- Fear life without their loved one

Common Experiences in Grief

Deep Sadness

Sadness may be constantly present after a loss or it may hit all of a sudden. Some kids feel:

- Lonely
- Like there is a hole in the center of their life
- Deep yearning, like they are reliving all their sadness

Hope and Personal Growth

After a while, children and teens start to look toward the future with hope, even though their heart still aches for their loved one sometimes. They may:

- Have new confidence in themselves
- Want to explore new interests
- Feel more empathy for others

Physical Symptoms

Grief can cause a variety of physical symptoms, including:

- Weight loss or gain
- Extreme fatigue
- Sleep disturbances
- Nausea

Other Behaviors:

- Feelings of anxiety
- Crying
- Anger and irritability
- Sleeplessness
- Changes in appetite
- Decreased activity
- Increased sensitivity
- Short temper
- Avoidance
- Difficulty concentrating
- Nightmares
- Withdrawn and isolated
- Headaches
- Stomach aches
- Increased fatigue

Common Myths About Grieving Children

- If a child is not crying or expressing sadness, they aren't grieving
- Children don't grieve
- The death of a loved one is the only major loss children and adolescents experience
- Children should be shielded from loss
- Children should not go to funerals
- Children get over loss quickly
- Children are permanently scarred by loss
- Talking with children and adolescents is the only effective approach in dealing with loss
- Children will get more upset if they see their parents cry



(Southern Tier Hospice and Palliative Care, 2009)

Behaviors That May be Cause for Concern in Children and Adolescents

- Child pretends nothing has happened
- Unable or unwilling to socialize with other children
- Becomes involved with drugs
- Begins committing serious acts of social delinquency
- The child or teen has a difficult relationship with the deceased, or behaves poorly with other family members
- Frequent panic attacks
- Threatening suicide or to harm themselves or others
- Physically assaults others or is cruel to animals
- Sexually promiscuous behavior
- Steady decline in school grades and/or attendance at school

When these signs are present, referral should be made to a counselor or therapist for further agency assessment, or referral should be made to a community agency specializing in assisting with the demonstrated behavior.

What to Say to Your Child and Teen

It's OK to say, "I don't know".

- If there are feelings of shame or guilt over behaviors or actions that have taken place, emphasize that no one ever taught them to react in such a situation, that the child did not choose for this to happen, and that they are not responsible for what has happened.
- ***"It can make a person really angry to have someone go away and not come back. Most people feel awful when someone they love dies."*** Identifying a feeling and hearing that there is nothing wrong with it can be a big help to a child and can make it easier to talk more about it. If the child is talking about revenge, ask about his or her plan and talk about realistic responses. Discuss additional ways to not let revenge take control.
- If a child reports that they are "not afraid of anything anymore" be more cautious, as they may not act safely in potentially dangerous situations, or with others who may place them at risk.
- Tell the child how sorry you are and offer him or her a hug if you want.
- Share a happy memory of the person who has died. Honoring and memorializing our loved ones is very important.
- Play and laugh with the child if possible; try to meet them at their level.
- Acknowledge that grieving is a process that takes time.
- Be aware that often thoughts and feelings of teens can be contradictory and inconsistent. Allow teens to express their thoughts and feelings without pointing out the inconsistencies.

What Not to Say to Your Child and Teen

“Grandpa will sleep forever” - this explanation may result in the child’s fear of going to bed or to sleep

“Daddy went away on a long trip and won’t be back for a long time”. - The child may wonder why their loved one left without saying goodbye. Eventually the child will realize Daddy isn’t coming back and feel that something he did caused him to leave.

“It is God’s Will”. - The child will not understand a God who takes a loved one because he/she needs that person to himself/herself.

“God took him because he was so good”. - The child may decide to be bad so God won’t take him, too.

“John was sick and went to the hospital where he died”. - The child will need an explanation about “little” and “big” sicknesses. Otherwise, he/she may be extremely fearful if they or someone they love has to go to the hospital in the future.

“Now, you’re the man/woman of the family”.

“You need to carry on for the surviving parent”.

“Try to be good for your mother/father; they are having a hard time right now”.

(Southern Tier Hospice and Palliative Care, 2009)

Activities to Promote Healing for Your Family

1. Volunteer as a family for a charity or cause that was meaningful to your lost loved one. (Example: town clean-up, senior citizens' center, soup kitchen).
2. Construct a memory jar about your loved one. Have family members write down memories that they have shared together on scrap pieces of paper. Put them in a jar and pull one out during a difficult or sad time.
3. Create a "worry box" for the family. Encourage each member to write or draw feelings of guilt, regret, fear, or worry and place them into the box. Burn the box and papers in a fireplace or fire pit.
4. Make a family scrapbook of photos, drawings, and mementos that memorialize your lost loved one. Make a list of his/her talents, characteristics, favorite things. Be sure to include blank pages for adding memories as time goes by.
5. Participate in memorial activities, such as creating a memorial garden or mural, to honor your loved one.

(Southern Tier Hospice and Palliative Care, 2009)

This season I am thankful for:

My mind

That still remembers you,

My voice

That still speaks of you,

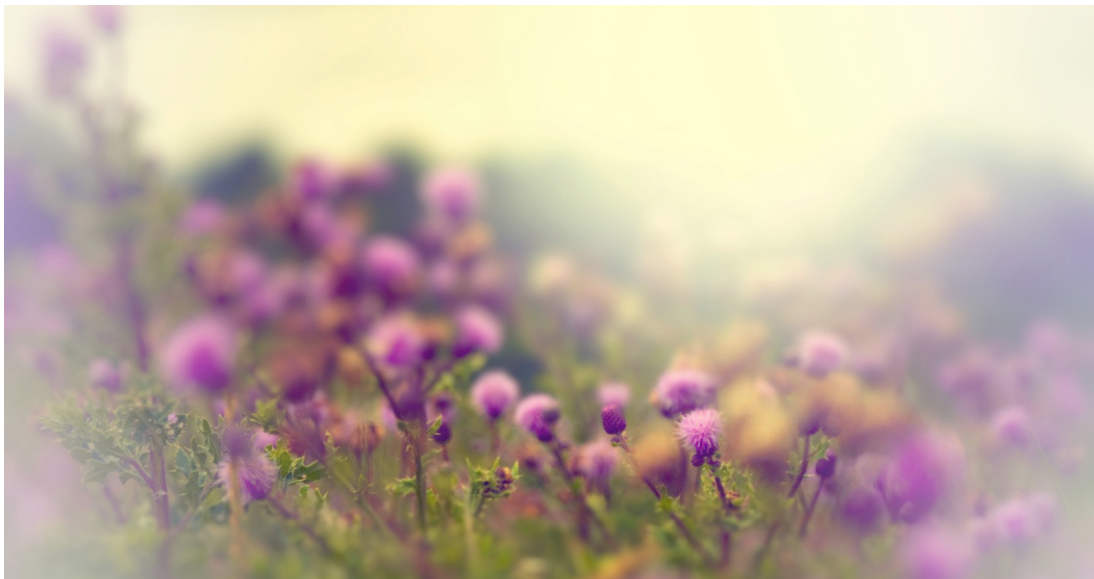
My spirit

That still hears you,

My heart

That still loves you

~ Tanya Lord



For My Grandma

By Priscilla OI

*Bottled up inside
Are the words I never said,
The feelings that I hide inside
Are the lines I never read*

*You can see it in my eyes
Read it on my face
Trapped inside are lies
Of the past I can't replace*

*With memories that are fading
That seems to go away
Why can't I be happier
Today's a brand new day*

*Yesterdays are over
Though the hurting is not
Nothing lasts forever
I must cherish what I got*

*The hurt I'm feeling now
Won't disappear over night
But someday, some how
Everthing will turn out all right*

*No more wishing for the past
It was meant to be
It did not last long
So now I will set you free*

SUPPORTING YOU
EMBRACING FAMILY
STRENGTHENING
COMMUNITY

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*CareFirst is a not-for-profit community-based program providing residents of
Chemung, Schuyler, and Steuben counties of New York State with complete
hospice, palliative care, and grief services.*

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